

National Coalition of Mental Health Consumer/Survivor Organizations

DRAFT White Paper:

National Recovery and Empowerment Initiative

October 23, 2008

(These policies were the work of 15 persons, mostly consumer/survivors in early 2008. They were based on the policy priorities of the National Coalition which were selected at the annual meeting in Oct., 2007)

Introduction: The National Coalition proposes that the federal government adopt a **National Recovery and Empowerment Initiative (NREI)**. Only a move this comprehensive would address the multiple areas of government action that need to be transformed in order to shift the paradigm of understanding and supports needed for persons with mental illness to recover and to live independently in the community. The core values of the NREI would be the components of recovery agreed upon at the December, 2004 SAMHSA sponsored consensus meeting: self-determination, hope, respect, peer support, person-centered planning, empowerment, and holistic care (www.samhsa.gov/pubs/mhc/MHC_NCcrecovery.htm). The role of the federal government will be to carry out the mandate of the Olmstead Decision as articulated in the New Freedom Commission by facilitating the transformation of mental health care and the larger community supports to a recovery-oriented system. The NREI would ensure the meaningful involvement of consumers and families in training, education, service delivery, policy, planning, evaluation, and research at all organizational levels

Overall Goal for NREI: To empower every individual to develop and recover a full life as an active citizen in his or her community

Policy 1. Public education and workforce training in recovery

Summary: In order to shift the mental health system and society from an illness, individually focused approach to a wellness, recovery, holistically, systemically- oriented approach, there needs to be widespread peer- and family-led education and training in wellness and recovery.

Policy 1a. Public Education on wellness, resiliency, and recovery to enable all citizens to be active participants in their communities and reach their full potential

Proposed activities: administration will build on its Campaign for Recovery, by teaching all Americans including all federal employees, that recovery from all mental health issues is possible. The campaign will also raise awareness regarding the impact that trauma has on mental health. Educational stories of hope, empowerment,

independence, and recovery would be played on public television; schools would teach group social skills, respectful communication, conflict resolution, building resiliency, communicating with people of different cultural groups; Self-help and peer support skills will be taught to persons challenged with mental health needs and their families and friends. Providers will be taught to forge human connections and develop human relationships based on sharing power and shared decision-making. They will develop and model a renewed sense of humanity. Communities would be built on celebrating and honoring cultural and human differences.

Policy 1b. Train and retrain the workforce in recovery and wellness

The newly formed Administration on Empowerment and Recovery (see below) will launch a provider training program on mental health recovery including the impact of trauma on mental health. Providers will be taught to forge human connections and develop human relationships based on sharing power and shared decision-making. People with the lived experience of mental health recovery will participate in the design and the delivery of the curriculum. Any university receiving Federal funding will be required to establish a recovery-based curriculum. Persons with lived experience of mental health recovery will be given stipends. There will be a national program to expand peer support specialists across the nation.

Policy 2. Fund a network of state, regional and national consumer-run technical assistance (TA) centers and advocacy groups

Summary: In order to ensure that mental health consumers and their families are meaningfully engaged in the transformation of the mental health system SAMHSA will fund statewide, regional and national TA/advocacy organizations.

Activities: This national network would be established by funding a statewide consumer-run and family-run network in every state at a level needed to ensure its basic functioning. The statewide consumer-run groups should be sustained by ensuring that 20% of each state's block grant money is dedicated to support of such networks, or the development of them in states that are developing them. A national network of regional and national technical assistance centers would support these statewide networks.

Policy 3: Develop alternatives to hospitalization and institutionalization

Summary: In order to reduce the costs, trauma, recidivism, and institutional roles produced by hospitalization, the National Coalition recommends community-based crisis alternatives with strong peer involvement which would include: crisis support planning, peer-run crisis centers, respite centers, in-home supports, crisis teams, and root cause analysis of crises

Activities: Community and home-based crisis options that are trauma-informed and are designed to acknowledge and build on the skills and resources that individuals and communities need to reinforce resilience, wellness, relationships and community integration. Examples include:

1. Small residential hospital alternatives such as Soteria House in Alaska and Windhorse in Boulder, CO.
2. Peer-run crisis programs and telephone support such as The Wellness and Recovery Center in Maine, Rose House in New York, The Wellness Center in Georgia and Stepping Stone in New Hampshire.
3. In-home and outreach support such as Dialogue Therapy in Finland, Mind and Body and WIT in New Zealand, and Windhorse in MA.
4. Recovery and crisis response skills training- to law enforcement, corrections and social service workers including Crisis Intervention Teams
5. 24/7 triage and warm line services staffed by peers and supported by clinical experts
6. Root cause analysis of every crisis to understand the deeper systemic causes of each crisis, and how to make continuous quality systems improvements, to prevent crises from recurring.

Policy 4: Creating homes and ending homelessness

Summary: Safe, affordable, accessible homes are needed so that individuals with mental health problems are not warehoused in institutions, including jails and nursing homes, and are homeless. Homelessness affects more than 3 million Americans every year, including families, children, youth, veterans, and those with mental illness and addictions. Solutions include permanent housing with supportive services, flexibility at the local level to prioritize need, and policies that support everyone in exiting homelessness.

Activities: First and foremost the federal and state governments need to make more units of affordable housing available either through building new units or through an expansion of Section 8 and other subsidy programs (see the section on housing). At least 560,000 persons with mental illness are paying more than 50% of their income for housing (HUD report, 2001). This means there needs to be at least this many new voucher programs and/or new housing units developed for this population. Wherever possible, people should be encouraged to buy their own home.

Supportive housing, Supportive housing, where the worker meets the consumer where they live in the community needs to be expanded. Supported housing is a recovery-oriented, evidence-based practice because it increases autonomy and choice (www.fanniemaefoundation.org/programs). Consumer-run supportive housing such as Main St. housing run by On Our Own of Maryland and Community Support Program (CSP) of NJ have an added advantage of decreasing the stigma and increasing empathy because the management staff can relate as peers as well as administrators.

We know how to end homelessness. We stand on the verge of a shift in how we as a nation approach homelessness. We know what works: moving people quickly into permanent housing with supportive services to keep them healthy and housed; focusing

on preventing homelessness in the first place; and developing a culture that offers support, not blame, as people move toward recovery and reintegrate into their communities. To end homelessness, we must sustain and expand federal, state, and local programs that show results in helping people exit homelessness and retain housing. We must honor the need of communities to have flexibility to implement a range of housing and service options that best meet local needs. And finally, we must recognize that all people who experience the horrors of homelessness—individuals, families, youth, veterans, those with and without disabilities—are worthy of help and support along the way.

Policy 5: Medicaid reforms to assist in transformation to a recovery oriented system

Summary: Medicaid and Medicare funding will be transformed from a narrow medical, institutional basis to a recovery and wellness orientation by reimbursing community-based, self-directed, peer-delivered, holistic care. *A Recovery Waiver* (in accordance with the Deficit Reduction Act) would be developed through collaboration between the consumer and family advisory board, rehabilitation experts, and CMS staff. This waiver would be the primary tool by which Medicaid funding would be directed towards recovery-oriented services. The waiver would stipulate that if a state could demonstrate that it had instituted a full array of recovery and rehabilitation services, and could demonstrate that all of the mental health Medicaid expenditures are under a publicly regulated, managed care contract, it could waive the IMD (Institute of Mental Disease: any facility with more than 16 beds in which more than 50% of the residents are psychiatric patients) exclusion. A full array of such services would include but not be limited to:

Policy 5a. Personal self-determination accounts

Summary: To increase the consumer control and consumer choice, persons with psychiatric disabilities should have a self-determination account, broker, and life plan by which they could budget and pay for a variety of community services

Activities: The fundamental components of the model are:

1. Carrying out a life analysis and the development of a life plan (based on the principles of person centered planning which is outlined under policy #5d),
2. Establishing with the assistance of a life coach a budget distributing money available between clinical recovery services (services by a clinic) and recovery support (peer delivered services and recovery enhancements (such as a computer)
3. Having a fiscal agency which is independent and does not administer services (One of the most important components of the model is that the fiscal entity, that manages the participant's budgets and provides funding for the program, must be an independent agent that does not provide paid mental health services other than the management of the program (Haine and Spaulding-Givens, 2007)
4. Program evaluation which has found positive results in terms of community integration: 75 percent of the ratings indicated the presence of these conditions, with relative strengths in areas such as working toward personal goals, satisfied

expectations, daily routine, interaction in the community, choice of service options, and exercising rights. (Hall, 2007).

Policy 5b: Person-driven recovery and resilience planning

Summary: Whereas traditional mental health care has consisted of professionally-driven treatment planning without significant consumer or family involvement, person-centered recovery planning, is a process by which the consumer and their family's hopes and goals determine their recovery plan with the professionals collaborating as facilitators

Activities: National training of consumers, families, and providers in person-driven planning, based on the principles it is based upon, and asking the consumer what they want and providing it:

- Holistic rather than a symptom reduction perspective
- Consumer-as-person and not diminished or dehumanized
- The sharing of power and responsibility in decision making
- The recognition of a therapeutic alliance and partnership
- Provider-as-person, not merely a position of authority

Perhaps the most important element of change would be to change the Medicaid funding requirements. Self-determination accounts (see policy 5a) would place more of the control of funding in the hands of the consumer, and thereby clinicians who met the consumers' goals would be rewarded by receiving more business. In addition, financial incentives could be instituted that rewarded the degree to which recovery planning reflected the dreams and goals of the consumer. Peer administered evaluations of services and supports using an instrument such as the ROSI (Dumont, et al, 2005. *Piloting the Recovery Oriented Systems Indicators (ROSI) Administrative Data Profile and Consumer Self-Report Survey*, www.power2u.org/resources) could measure the degree to which clinicians and peer specialists work with consumers in a person-centered fashion.

Policy 5c. Medicaid reimbursement of rehabilitation services

Summary: The state Medicaid authorities narrowly interpret CMS's term medical necessity to mean only medically directed services, disallowing many rehabilitative services and to remedy this misinterpretation, it is proposed that CMS issue interpretive guidelines to the states which allow them to broaden the definition of medical necessity to include rehabilitative necessity and community integration and in so doing fund a wider array of recovery services.

Activities: The transformation needed in the Medicaid system is to move from a "deficits" model to a "strengths" model of treatment. That is, build on a person's strengths so they move beyond returning to a symptom-free life. In order to do this, the "medical necessity" definition needs to be broadened to "rehabilitative necessity and community integration". Services that assist a person's re-integration into the community need to be reimbursable. These would include the staff time necessary to help someone take advantage of housing and employment programs offered in the community. There is a precedent for such an interpretation of medical necessity. Michigan's Medicaid

Authority made just such a change. Because there is no set definition of medical necessity at the federal level, CMS could facilitate this shift in services by crafting interpretive guidelines to inform the state Medicaid Authorities that they could broaden medical necessity. Furthermore, CMS through collaboration with SAMHSA, could encourage the State Medicaid Directors to invite consumer leaders and advocates to their national meetings to engage in recovery dialogues which help enlighten those directors about the importance of shifting to a recovery-oriented Medicaid system.

These changes would allow Medicaid support for a person establishing a home (supportive housing), obtaining and keeping a job (supportive employment) and returning to school (supportive education).

Policy 5d: Peer support reimbursement by Medicaid

Summary: Peer workers (known as Peer Support or Peer Specialist workers) have been shown to be effective in providing recovery-based services to people with psychiatric disabilities. In order to ensure that the values of peer support are always maintained in this work, training and supervision should be developed and implemented by people with lived experience of psychiatric disability.

Activities: We believe that peer workers must remain true to the values of peer support, or the potential impact of this service is lost. This goal has been achieved in Arizona, with the approval of their state Medicaid Office and CMS. We recommend that this recovery-based peer support be Medicaid reimbursable in all states. To do this, we urge that:

- Peer support training should be developed and implemented by persons with lived experience of mental health recovery.
- Supervision of peer workers should be conducted by persons with lived experience, similar job experience, plus additional supervisory training. To develop a pool of such supervisors, the first supervisors could be peers with clinical training.
- Medicaid should encourage a dialogue among states to showcase creative programs with effective outcomes and allow states to learn from each other.
- In accordance with the President's New Freedom Commission, Medicaid should recognize that peer workers have a valued place, and encourage collaborative approaches to ensuring high-quality services that are consistent with recovery values and principles.
- Peer support in a variety of community and inpatient settings should be regularly reimbursable under Medicaid when the above requirements are met.

Policy 5e: Medicaid reimbursement of Consumer Directed Personal Care Assistants (PCA) in Mental Health

Summary: Though most state's Medicaid authorities will not pay for personal care assistants for mental health, the Federal Medicaid guidelines authorize this service and CMS could inform the field of this by disseminating interpretive guidelines to that effect

Proposal: That CMS issue interpretive guidelines to the state Medicaid Authorities detailing that ways that PCA's can be used for mental health. The guidelines could draw on Oregon and New York as examples. One element of such guidelines would be to include activities of community living in the definition of services a PCA could be reimbursed for. The guidelines should also point out: for a personal care assistant to be maximally effective in a consumer's life, the care must be consumer-directed. This means the consumer dictates the nature of the help, the quantity of the help and the duration of the help. The result is often empowering, as the consumer gains confidence through managing this aspect of their life and is able to benefit from greater social interaction. A person would be evaluated by a mental health professional who would decide the number of hours of PCA support needed for the person to accomplishing their recovery goals. Service recipients would hire a person with whom they feel comfortable through a nonprofit organization (preferably a peer support center or community mental health service center). Service recipients would be reevaluated periodically to assure eligibility and also that recovery plans are being implemented. This policy would be integrated with the other Medicaid policies such as self-determination budgeting and person centered planning.

A recent study by the PSU School of Social Work found that consumers working with PCAs had significantly higher levels of empowerment, PCA-direction confidence and behavior, and quality of life compared with consumers who were on a waiting list to participate in the service. States should also evaluate the implementation of this service and give reports to CMS.

Policy 6: Protection of Rights of People with Psychiatric Disabilities

Summary: We propose that people with psychiatric disabilities be treated as all other individuals, with dignity and respect, and that their right to self-determination and all other rights accorded to other citizens and members of society be protected.

Proposals:

1. Reduce with a goal of eliminating seclusion and restraint.
2. Implement optimal safeguards for ensuring that all procedures and treatments funded by federal money or carried out in federally funded facilities demonstrate that potential recipients have given their fully informed consent.
3. Establish federal guidelines for the exercise of due process in all commitment and guardianship hearings for persons in civil or military hospitals, jails, prisons, or in the community. This would include an independent evaluation by a psychiatrist with no financial or clinical stake in the outcome.
4. Increase funding of Protection and Advocacy agencies in each state to enable them to monitor these rights in the community as well as in institutions.
5. Enforce the Americans with Disabilities Act and Fair Housing Act. EEOC and the Justice Department need better funding and training to be able to better enforce these laws.
6. Expand the capacity of Federally funded Protection and Advocacy for Mental Illness (PAIMIs) organizations in each state to ensure that they can adequately

protect the rights of persons with psychiatric disabilities in the community as well as institutions

7. Ensure the release of the Reports by the Rights Subcommittee, Consumer Issues Subcommittee, and every other subcommittee of the New Freedom Commission on Mental Health that have not yet been released by the present administration
8. "Laws that allow the use of involuntary treatments such as forced drugging and inpatient and outpatient commitment should be viewed as inherently suspect, because they are incompatible with the principle of self-determination. Public policy needs to move in the direction of a totally voluntary, community-based mental health system that safeguards human dignity and respects individual autonomy." (NCD Report, From Privileges to Rights, 2000)

Policy 7: Children's Community-based Services

Summary: Whereas children with mental health needs are often placed in institutions far from their home and at great cost, research shows that a wraparound approach, which integrates the child with their family and community, has better results and less costly in dollars and trauma.

Proposal: We recommend a wraparound approach to services for children. When compared to group homes, hospitalization and incarceration, wraparound results in great declines in behavior problems, greater increases in functioning, higher stability in residential placement and an increased likelihood of permanent placement.

A panel of nationwide experts has agreed upon the core elements of wraparound services: which are key to the process success, include:

- **Interagency Collaboration** – requires that the resources usually held in strict silos be shared to create an expansive array of services.
- **Community-based services**- should be provided in the local community or rural area where the child and his/her family live. Restrictive or institutional care should only be accessed for brief stabilization periods.
- **Individualized care** – is based on the specific needs of the child and/or family, and not on a menu of services. It can include both traditional and non-traditional services uniquely tailored to meet the specific needs and strengths of the child/family.
- **Family-driven, family-focused** – services are those where the family and child have direct input and ownership in the decision making process. Families and youth are listened to and heard at every step in the wraparound process.
- **Strength-based services** – necessitates that the positive aspects of the child, family and community are a vital part of the holistic planning and service process. While the deficits are taken into account, the wraparound process focuses on strengths as the basis of its services.

Unconditional care – requires that service providers never give up on a child or family due to severity of behavior; instead services are changed as the needs of the child or family change. Children and families are never rejected from services thus creating continuity of care and breaking the extremely destructive cycle of movement from one placement to another.

Policy 8: Coordination of agencies involved with recovery from MH Issues

Summary: In order to full fill the need for Federal coordination of mental health services, research, training, and supports a new agency, the Administration on MH Recovery will be created.

Proposal: It is recommended that within 60 days of office, the President issue an Executive Order establishing a Federal Interagency task force on mental health. The task force will be chaired by the Secretary of HHS and include senior leadership from DOD, VA, SAMHSA, FDA, NIH/NIMH, CMS, CDC, SSA, HUD, DOL, DOE, DOJ and other Federal representatives as well as people with psychiatric disabilities or a history there of. It will be charged with creating and implementing a blueprint for promoting recovery and wellness. This will include the improved coordination of a Federal response and the consolidation of mental health initiatives into a new Federal agency to assure that Americans with psychiatric disabilities can recover and participate fully in our communities. The new Federal agency will be based within the Department of HHS and will be entitled the Administration on Mental Health Recovery (AMHR), will include the efforts of SAMHSA's Center for Mental Health Services, the services research efforts of the National Institute of Mental Health, research and training programs from NIDRR, and the funding for MH by CMS. It functions will be to promote recovery from mental illness by prevention and health promotion efforts, mental health workforce development, surveillance and other data collection activities to monitor effectiveness, transportation, housing, employment, and others as determined by the Mental Health Task Force. AMHR will provide a new Federal focus on mental health and will be guided by a citizen board which will consist of at least 25% persons with psychiatric disabilities and 25% family members.

Policy 9. Employment and Social Security

Policy 9a. Recovery through Social Security reform and supported employment

Summary: Very few people who have psychiatric disabilities and are on SSI and SSDI return to work. To create avenues back to work for persons with psychiatric disabilities we must create ways to overcome the existing barriers and disincentives presently in place.

Proposals: RSA, especially through the state grant programs, needs to change its view to a more flexible allowance for the often cyclical nature of major mental illnesses. It needs to improve the ticket to work program to fund supported employment programs whose funding does not depend on case closures.

SSA needs to transform SSI and SSDI so that the rules encourage work and independence. Mental illnesses tend toward relapse or cycles. Consequently, for SSI/SSDI to have a positive effect on persons with mental illnesses, more flexible "on

and off switches” are needed. This would encourage people to try work, get out and risk failure knowing that a restart is possible and encouraged

Policy 9b. Recovery through financial literacy

Summary: A significant portion of people living with mental illness find themselves living a life of poverty, unemployment, under employment, homelessness, and dependent on the mental health provider system. When persons with psychiatric disabilities learn financial literacy skills and build Individual Development Accounts (IDAs) they can begin to emerge from poverty.

Proposal: Financial services aimed at promoting financial literacy, responsibility for money management, development of long-term savings skills and habits, and acquisition of assets can enhance recovery from mental illness through economic gains and financial independence.

People need support, encouragement and flexibility to persevere towards their personal economic self-sufficiency goals. With the right incentives, support, and education, individuals can save money.

Encourage the use of Individual Development Accounts (IDAs) to enable persons with psychiatric disabilities to save money for home ownership, education, or a small business.

Policy 10. Understanding the impact and prevalence of trauma

Summary: The prevalence of trauma and its impact on the health and well being of individuals and communities needs to be recognized across the spectrum of mental health and human services. Providers need to be trained in implementing culturally competent trauma-informed treatment interventions; and flexible alternative services, including peer-run services, need to be available.

Proposal: Assessments need to include an evaluation of trauma and the impact it has on an individual’s mental health and healthcare status. Alternative options to traditional mental health services should be part of the healing support system. Peer support and self-direction are integral to healing from trauma. Policies, procedures, and practices need to be developed that minimize retraumatization and create emotionally empowering and safe environments. Providers need to understand the importance of cultural competence to meet the needs of specific communities and substantial training needs to occur across the spectrum of service users and peers as well as providers